

## CLINICAL ETHICS

## The unwitting sacrifice problem

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The diagnosis of bipolar disorder has been linked to giftedness of various sorts and this raises a special problem in that it is likely that the condition has a genetic basis. Therefore it seems possible that in the near future we will be able to detect and eliminate the gene predisposing to the disorder. This may mean, however, that, as a society, we lose the associated gifts. We might then face a difficult decision either way in that it is unclear that we are preventing an unalloyed bad when we diagnose and eliminate bipolar disorder through prenatal genetic testing and yet if we allow the individual to be born we are condemning that person to being an unwitting sacrifice in that they might well suffer considerable net distress as a result of our need to keep our gene pool enriched in the relevant way.

Kay Redfield Jamison traces a number of lineages in Western culture in which the propensity to bipolar disorder (BD) and the existence of exceptional talent, especially creativity, seem to be linked.<sup>1</sup> She argues for the eminently plausible position that there is a genetic basis for this disorder and speculates about the ethical challenges that are posed by that fact. This paper aims to find a mode of ethical thinking which can get to grips with the issues that are raised by the possible association between a genetic disorder and serious effects on the lives of affected human beings.

Once we isolate and learn to detect a genetic abnormality that predisposes an individual to develop a genetically mediated disorder, we are forced to make certain choices. When the knowledge can be gained before birth and so early after conception that we are dealing with pre-embryos we might ask whether we should: i. select embryos without the genetic defect and discard or terminate the lives of others, or ii. try to modify the genetic material of affected individuals so that they develop with a more "normal" genetic constitution. Consideration of these ethical issues is pressing as a result of the human genome project which, for the first time, offers us the hope of understanding and potentially altering the genetic resources of the human race. Bipolar disorder is a great test case for those issues in that, as Redfield Jamison notes: "[m]anic depressive illness appears to convey its advantages not only through its relation to the artistic temperament and imagination, but through its influence on many eminent scientists

as well as business, religious, military, and political leaders" (Redfield Jamison,<sup>1</sup> p 252).

There seems little doubt that the predisposition to BD goes along with an enhanced tendency to excel in creative and other endeavours and the problematic possibility is that this is a widespread and general association in the human genome which has effects beyond those individuals that actually develop BD.

Andreasson, reflecting on these issues in the light of her prevalence studies among creative individuals, remarks: "these results do suggest that affective disorder may produce some cultural advantages for society as a whole, in spite of the individual pain and suffering that it also causes. Affective disorder may be both a 'hereditary taint and a hereditary gift'."<sup>2</sup> Notice that the giftedness and the variable manifestations of the disease mean that we cannot say with certainty that a given individual will have a bad life but all that is needed to make the problem pressing is that the condition as a whole brings a net burden of harm to those who develop it (an assessment implicit in it qualifying as a disorder requiring treatment).

The association gives rise to a raft of closely interrelated ethical problems which can usefully be pursued by spelling out what I will call *the unwitting sacrifice problem*: if we allow individuals to be born who have a predictable disposition to develop a condition associated with severe harms and yet offer society at large certain advantages, those individuals are born as unwitting sacrifices to our societal desire for certain benefits.

Is it right to allow somebody to be an unwitting sacrifice in this way? We could put this quite starkly and imagine ourselves addressing the embryo that we know to have the relevant genetic alteration.

We are going to continue your life because although you do not know it and have not chosen it you are likely to bring certain advantages to us. The price you pay for us receiving these advantages is that you will be affected by a somewhat unpredictable disease which may make you mad from time to time, cause you to go through periods of black despair and personal suffering, predispose you to become addicted to noxious substances, and perhaps even cause you to take your own life in a final desperate act to escape your torment. You may not develop the worst of these problems and you may have moments of great joy but there is a very

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**Abbreviations:** BP, bipolar disorder; GIU, general impersonal utility

significant risk of these evils befalling you. We could modify the genes that may have these effects in you but because of the possible benefits you may bring to the rest of us we have chosen not to. We are not going to ask for your assent to this choice we are making.

## THE ARGUMENTS

When we attempt to articulate the arguments bearing on this ethical problem, we are brought face to face with issues and modes of argumentation in bioethics that are relevant beyond the context of inherited genetic disorders.

1. We should avoid predictable genetic harm
  - 1.1. Some gifted human beings run a risk of serious genetic harm.
  - 1.2. The gifts this group bring to us benefit us as a society.
  - 1.3. It is wrong to put anybody at risk of harm to benefit others.
  - 1.4. We can reduce the risk of genetic harms by genetic intervention.
  - 1.5. We should prevent these harms where possible by genetic intervention.

This argument looks straightforward when the relevant genetic harm can be avoided without there being countervailing ethical considerations but, in fact, all prevention of genetic harm carries implications which may or may not be ethically weighty in and of themselves. For instance, we might think that terminating an embryonic life does not raise countervailing considerations, but a moment's thought about embryos and the debates about their moral status soon reveals that it is not that simple.<sup>3</sup>

If, for instance, the genetic harm related to giftedness was generally associated with a life that most affected people regarded as "a great life", then terminating the genetically affected pregnancy would itself entail the loss of a life with overall positive value and therefore would cause more harm than good. Thus the argument would fail. It would also be undermined if the life preserving genetic intervention mitigated both the "highs" and the "lows" in such a way as to expunge certain goods associated with a life of the relevant type (we will see that this is similar to the effects of the most widely used drugs for the disorder). In either case we lose certain benefits in trying to avoid a harm and we are forced to do the almost impossible calculations affecting a mix of benefits and burdens that characterises any human life.<sup>4</sup>

In most cases the weighting of such harms and benefits is done in accordance with a principle such as autonomy whereby the relevant individual chooses the course of action resulting in a predicted mix of foreseeable goods and harms that most appeals to him or her. On this basis one might argue that any harm whatsoever can be consented to for the sake of what the person concerned regards as a greater good, so that argument 1 should be modified by reworking 1.5 as follows.

1.5 We can only prevent those harms where the individual consents to the requisite intervention.

This straightforward appeal to harms and good within the same human life and according to an identifiable value hierarchy cannot, however, get any purchase in the present situation because of the individual in question. We are contemplating either preventing a life from reaching the point where such a value hierarchy exists or changing the person in ways that would affect their value hierarchy.

Therefore the only way to get a sustainable conclusion out of the original is to insert a suitably strong (and absolute) premise in place of the autonomy/consent premise 1.5. Such a premise as 1B3 below will do the job, yielding a rejigged argument as follows.

1B We should eliminate all unconsented to predictable harms.

- 1B1. Some gifted people inherit a risk of serious harm along with their giftedness.
- 1B2. Their giftedness benefits society as a whole.
- 1B3. It is wrong to expose an unconsenting person to risk of harm so as to benefit others.
- 1B4a. We cannot get consent to undergo risk from an embryo and we can eliminate the risk of harm by genetic intervention. *Therefore...*
- 1B5. We should prevent the harm where possible by genetic intervention.

This modified argument succeeds only if premise 1B3 is uncontroversial, but it is not because we can easily create an ancillary objective premise that derails the argument.

The ancillary premise arises because many ethicists accept some version of a "general impersonal utility" (GIU) premise<sup>5</sup> and regard consent and autonomy as only *prima facie* principles which can be overturned by other considerations (as for instance when we do not get consent to resuscitate a potential suicide victim, or we act to save a comatose patient's life).

GIU: A harm should only be avoided if the required intervention improves the overall and objective sum of harms and benefits.

The effect of this is to make 1B5 vulnerable to a weighting of the harm involved in the genetic disorder and the harms or losses of benefit incurred by avoiding it, so that it becomes arguable whether we ought to prevent the harm even if the individual does not consent to undergo it. Taking GIU seriously, however, spawns three other arguments that need to be addressed in that they have implications for the general basis for genetic counselling and the potential eugenic implications of such counselling.

2. We should produce the best human lives we can.

- 2.1 Individual A has a genome that is likely to produce suffering in life.
- 2.2 That suffering would be avoided by replacing individual A with individual B.
- 2.3 Suffering should, where possible, be avoided.
- 2.4 We should not produce A but rather should produce B.

Notice that there is a probability of harm not a certainty for the genetically affected individual (A) but the presumption implicit in the thought that BD is a disorder is reflected in 2.1. This argument immediately provokes two intuitions that run counter to its conclusion and need to be dealt with by refuting the arguments that capture them.

3. Any life is better than none.

- 3.1 Replacing A with a genetically normal individual avoids the risk that A will be condemned to living a damaged life.
- 3.2 Living a damaged life is better than living no life at all.

- 3.3 Replacing A entails that A is deprived of life.
- 3.4 A should not be replaced by B.

Even though argument 2 favours a “search and destroy” approach to many genetic abnormalities, argument 3 favours cherishing each life that comes into existence despite what might be seen as its shortcomings (a position strongly favoured by certain disability advocates). What is more, 3 is strengthened if we accept something like argument 4 (to which many subscribe in some form or other).

4. Each human life is unique and should be respected.
  - 4.1 Any human life is unique from its beginning and therefore irreplaceable.
  - 4.2 A human life, even a genetically abnormal one, is therefore irreplaceable.
  - 4.3 Nothing irreplaceable should be destroyed.
  - 4.4 A genetically affected pregnancy should not be terminated.

One could argue that replaceability is not necessarily the issue because all we are doing is avoiding a harm which might befall an individual and ensuring that the individual concerned leads a life without that harm as part of it. This may be true if a non-lethal means of avoiding the genetically determined harm is discovered. Even, however, if we were to find a non-lethal means of correcting a life altering genetic disorder we would still need to take a stance towards an oft repeated remark by an autistic person who, when asked if he would rather have been born without autism, answered: “You mean, would I rather not have been born at all and somebody else have been born in my place, because the autism is part of who I am”. If we take this remark seriously, we should be wary of classifications of moral decisions based purely on something as minimal as genetic identity at time of conception. Such a classification is often used to separate same person judgments, different person but same number of persons judgments, and different number (of persons) judgments.<sup>6</sup> This neat division appears to make certain types of reasoning clearer but will turn out to have limited relevance to the current debate because of the structure and universality of the arguments concerned (when relativised to possible worlds).

### THE INCONCLUSIVENESS OF THE ARGUMENTS IN THE UNWITTING SACRIFICE PROBLEM

If BD does have a significant morbidity and mortality, then bringing a child into the world who is likely to develop BD deliberately exposes an innocent and unconsenting human being to the risk of suffering (unmeasured and possibly mixed with some goods but quite possibly devastating to the point of provoking suicide) because of the gains that the rest of us may obtain from that person’s being among us.

The ethical objection to this choice is captured in argument 1B—that we should eliminate unconsented to harms when we can. That argument, however, is, in turn, undermined if we accept GIU—the general (or objective) impersonal utility claim—along with the estimate that the resulting benefits to society in general (and to the individual) outweigh the affected individual’s suffering.

The GIU premise is not, however, univocal as it depends on an assessment of the overall or objectively best sum of utilities. That sum may support the replacement of the potential individual afflicted by a genetic disease (A) with an unaffected but different individual (B) or it may not. The best thing to do turns on the possibly incalculable sums that are supposed to tip our moral intuitions one way or the other. Rather than delving into specious sums, however, we can cut

through the detailed consequential assessment by noticing that the GIU premise itself is highly contentious in the face of arguments such as Parfit’s repugnant conclusion: the idea that we should value a very large population whose lives are barely worth living over a less numerous but much more fulfilled set of human beings (Parfit,<sup>6</sup> pp 387 ff). The argument to the repugnant conclusion depends on the idea that the multiplier (a very large number of people) is more than enough to produce a sum of happiness from its very modest cofactor and therefore offsets the losses of utility in the lesser number of lives that would have otherwise been full of good things (in a less crowded world).

The GIU premise is also weak in the face of a significant liberty principle that many find independently plausible and that prefers autonomy or some cognate of it (as applied to existing individuals) over sums of collective good.<sup>7</sup> The effect of taking autonomy seriously is to relativise overall and objective harm (in some way that looks rationally defensible) to individuals whose wishes are taken seriously and thereby amount to rights (thus avoiding any justification of the abuse of a minority to pleasure the majority and focusing our attention on the quality or preference satisfaction of individual lives). This general endorsement of something like individual rights (or individual quality of life) over an impersonal quantity does, however, smack of a kind of chauvinism favouring a preferred set of actual individuals and ignores the big picture which includes possible individuals. The rational defence of that position, if we wish to be impartial in our treatment of all human individuals at all possible times, is hard. Quite apart from these general woes affecting the relevant arguments, we have an irresolvable problem with preimplantation or even early prenatal genetic selection because there is no uncontroversial individual preference base to appeal to when a given life with a genetic affliction of variable severity is ended or prevented from coming into existence for the sake of what looks like a better life.

Consider, for instance, argument 3 to the effect that any life is better than none. One might ask: “Better for whom?” We have two potential human beings in the offing and we beg the question by limiting its addressee to one of those (the actual rather than the possible alternative one).

Or consider a version focusing on one candidate for the privilege of being born: are there any circumstances in which it would be better for a given person not to be born?

It seems counterintuitive to argue that the non-existence of an individual is a better alternative than their existence if we concede that there are some goods in that individual’s life—the intuition captured in the saying “*Any life is better than none*”. It seems that the only way we could argue that this intuition should be rejected and that it actually is better for A not to have lived and B to have a life instead, is on the basis of something like the very suspect GIU premise (we should maximise the overall objective utility in the world).

Argument 3 is, however, itself highly questionable in that it seems to involve a straight preference for the possibly distorted and definitely self interested preference of individual A just because she/he exists and has these preferences. In the totality of possible worlds, however, (all the possible states of affairs that we have to take account of given the different decisions that could be made) these are exactly counterbalanced by the preferences of B who is born if A is terminated or not brought into existence. So where do we go from here?

We could go to something like argument 4 which puts an absolute value on human uniqueness (so that A is valuable no matter how the utilities pan out). On that basis it seems that one should favour the protection of A despite his/her prospective burden of genetically determined suffering. That



conclusion is, however, vulnerable to a similar move to the one already invoked whereby the uniqueness of A is viewed in the context of an array of possible worlds (or decisions that could be made and their likely consequences) in which case the uniqueness of B (who would be born if A is not) would counterbalance that of A. So, again, arguments of this kind get us no further ahead unless something other than general impersonal utility is at stake, something inseparable from actuality.

Given the inconclusiveness of this style of argumentation for the unwitting sacrifice problem (and its associated puzzles), we might wonder whether we can resolve the problem by moving to a non-utilitarian framework of moral argument on the basis that all premises calling on intuitions that seem to engage with highly abstract generalisations are difficult to get into any realistic kind of reflective equilibrium.

### VALUING LIFE OVER NON-LIFE

Let us concede that we cannot really compare life with non-life from a first person point of view because any person would be likely to say: "Of course it would be better that I had been born". This first person moral claim appeals beyond any small contributions one might make to an objective sum of meaningless, abstract, and incalculable quantities and invokes the thought that the world is different in some irreducible way because I am in it and that the difference is not one that we can discard with impunity. Such at least is part of the message of stories in films such as like *My Left Foot*, *It's a Wonderful Life* and *Forest Gump* and, intuitively, it seems resistant to the universalising "possible worlds" move on the basis of something like the importance of those to whom we are actually related.

Given the relatively weak claim that there is at least something that I and others value (or, better, ought to value) about my life (whoever I am), it seems difficult to accept the claim that no human being should ever have had to live any of the moments of life that I have had to live. That claim looks even more implausible if we are attracted to the idea that values to be found in different kinds of human life may be incommensurable. The combination of the irreplaceability of the individual and the incommensurability of different values makes it fairly hard to defend the idea that we can cut off a developing human being on the basis of features intrinsic to that human being's life that we regard as being of disvalue so as to justify the decision that that human life should never come into being. The impasse that this brings us to, with much wider implications than the unwitting sacrifice problem, suggests that we do need a different framework of ethical evaluation than that deployed so far.

The clues to the wider framework seem to lie in actuality, incommensurability of value, relatedness, and irreplaceability<sup>8</sup> and they admit a number of considerations. One might consider the prospective impacts of the developing life on others in the way we do when we endorse an abortion decision (in the extreme case because of the palpable threat posed by the developing life to the mother—a human being already among us). One might also consider the likelihood that the life of an individual might be marked by an absence of any meaningful experiences as a morally engaged being among us (as we do when we authorise termination or withdrawal of neonatal care because of severe fetal abnormality such as anencephaly). This last consideration may or may not be compounded by the first—a significant burden to others. We also can and do take into account the developmental trajectory of the individual and where we are on that trajectory, intuitively placing greater weight on an entity when it is closer to its valued form than when it is more distant from it—think, for instance, of a painting that starts with a brush stroke on an empty canvas.<sup>9</sup> All of these things

are, however, somewhat inconclusive and the waters are seriously muddled by a further curious phenomenon in the ethics of genetic conditions.

By and large, individuals with Huntington's disease, a disease which causes death in middle age preceded by an increasingly intrusive movement disorder and a variably distressing dementia, all favour genetic selection to eradicate their disease. They do so on the basis that new individuals should not be born with the disease. They think of those new individuals as being the offspring who are born of a particular couple, in a certain order, and with a certain sociohistorical location. Ordinarily we do not consider the children who are "discarded" and never have a chance of life (unless the abortion or miscarriage or whatever has impacted the consciousness of the individuals involved). Thus, those individuals who suffer from Huntington's disease who favour genetic selection to eradicate their disease do not consider the fact that each person born with the disease would nevertheless say that he or she is glad to have been born as being of any consequence either way in the push for genetic selection as a means of eradicating Huntington's disease. This seems odd; why do they not link their policy with the thought that individuals just like themselves might be deprived of a chance of life?

Similar empirical indicators to those which exist for Huntington's disease are not, as a matter of fact, available to help us decide about bipolar disease but when asked the question: "Would it be better that you had been born without your bipolar disorder?" sufferers commonly say exactly what autistic people say: "If I did not have my disorder I would be someone else". Their position is readily understandable the moment one reflects on the sort of changes in one's life that would make it so radically difficult that it becomes impossible to decide whether one would be "the same person". For a person who has this thought Parfit's non-identity problem (Parfit,<sup>6</sup> pp 351 ff) is phenomenologically real and we are asking whether the unique creation that is a human life should be discarded before it comes to being because there will be a significant amount of suffering entailed by living that life.

We must therefore ask: "How much suffering and how much countervailing goodness make it objectively better not to have a given unique human being among us and how active ought we to be in making such choices available to the people making the relevant decisions?" The general resolution of a problem such as this becomes even more difficult when we take seriously the thought "that health must always be seen in reference to individuals".<sup>10</sup> This thought is embedded in what has been called a theory of individual health which allows that things such as "surmounted sickness" may contribute to health and that some obvious diseases may have much less import for experienced health than what we might best call "maladies of the soul" (Danzon, *et al.*,<sup>10</sup> pp 17–18). This comment is based on the fact that individuals with serious diseases such as asthma, severe cardiac disease, hepatitis, and diabetes rated their experienced wellbeing significantly more highly than sufferers of somatisation disorder and neurotic depression.

We can plausibly finesse these almost intractable (how long is a piece of string) questions about the level and type of predicted suffering that would justify non-life by asking a different one: "Where we have no clear moral indication to act should we interfere with what nature provides on the basis that we think we know better?" We might acknowledge that we do have a *prima facie* justification for acting to intervene and change events in a favoured direction wherever we can demonstrate that an individual or group of human beings is thereby spared sufficient suffering or unwelcome intrusion and inconvenience in their lives that any person

would not want to take the risk of that “unacceptable badness” (Gillett,<sup>3</sup> p 183). We might, however, also be cautious about the move from *prima facie* justification to an “all in good reason” to do something because, particularly in the genetic lottery, we might be persuaded that nature (or providence otherwise unspecified) has been playing the odds for years and probably has a better game plan than the limited and fairly flatfooted or shortsighted strategies we might favour. We should not confuse this with any kind of blanket fatalism, because it is based on a considered judgment that moral reasoning is so evenly balanced on the issue that a rational call does not look likely. We should also notice that reductive accounts of the interests of nature in bare fecundity as distinct from anything like *eudaimonia*, ignore the mildly persuasive conjecture that nature has arranged things so that fecundity and wellbeing are not totally independent of one another.

### GENETIC SELECTION AND ETHICAL UNCERTAINTY

In genetic selection for or against any trait we constrain the choices open to a future individual based on a projection of harms and benefits. The responsibility incurred by imposing on a future individual a constrained set of choices that might impair that person's ability to opt for some of the goods available in the kaleidoscope of human life should, however, give us at least some pause. Whereas one might not easily be able to argue that selections of the sort currently available impair autonomous choice under most of its current formulations, there is an intuitive sense in which putting a person in a preconditioned position does prejudice or defeat that person's autonomy in a significant way.<sup>11</sup>

An alternative to respect for the presumptive choices of progenitors about what kinds of lives are worth living is hard to define (in all but the most clear cut of cases where we should act in the best interests of the future individual). However, prospective parents are often looking for some kind of guidance as to what might be a reasonable decision in the face of possible congenital abnormality and we therefore seem to need some form of individual respecting guidance in relation to these arguments to do with the unwitting sacrifice problem.

The impasse is, I would argue, best negotiated by a narratively informed attention to the individuals who are most affected and a concern to achieve an intuitive identification with their actual and potential stories. This effectively inserts into one of the most basic elements of bioethical reasoning—beneficence—a narrative orientation that, in turn, renders it somewhat recalcitrant to many of the abstract generalities currently propounded in debating policy.

When we look for this narrative orientation through imaginative identification and first person reports we find that some people with BD prefer the whole package (BD + the goods that their gifts bring them), despite their sufferings and trials, to the point where they are resistant to taking their medication—as close as we can get to a same person choice.<sup>12</sup> Therefore we can say that even the probabilistic harm associated with the chance of developing BD is not unalloyed. Bipolar disorder patients give us, through their choices in relation to medication with drugs such as Lithium that smooth the course of disease and spare them from their psychotic episodes and severe crises of depression, the best evidence possible that this is by no means a package to be rejected in its totality. Indeed such a position is what would be expected from Nietzsche's individualised conception of “health” and its curious relation to disease (and its overcoming) as has already been mentioned. Nietzsche remarks: “the determination of what is healthy for your body depends on your goal, your horizon, your energies, your impulses, your errors, and above all the ideals and phantasms of your

soul”.<sup>13</sup> The relatively unconstrained view of health and benefit that is implied by this very appealing Nietzschean idea of “individual health” warns us against any simplistic conceptions of benefit from the third person view that is required for genetic selection.

We can now return to the problem we began with. The problem, in its unmodified form can be expressed as follows:

1. Some individuals have a predictable disposition (evident before they can make life decisions) to develop a condition associated with severe harms.
2. Some of these individuals offer society at large certain advantages.
3. If we allow them to be born they will suffer these harms.
4. It is wrong to allow an unconsenting person to be a sacrifice to our societal desire for certain benefits.
5. These individuals should not be born as unwitting sacrifices.

The counterarguments to date add the following premise:

2b. The gifts are valued not only by society but also by those who have them despite the risks associated with them and they also benefit others.

3. then has to be modified to:

3b. If they are born they will experience this packet of harms and goods.

That then forces 5 to be recast as

5\* Individuals should not be born if we can predict they will receive a whole package (of risks and benefits to themselves and others) which they might judge, despite the harms, overall to be worthwhile.

This does not look persuasive, in fact it looks like what happens whenever we give birth to any human being only in this case it is with a few more clearly negative aspects. Therefore it is hard to get the original conclusion which licensed a search and destroy policy towards genetic abnormalities:

We should prevent these harms where possible by genetic intervention.

The following dialectical balance sheet seems therefore to summarise the position we are left in.

Argument 1 (to support genetic intervention to prevent harm) fails because we cannot enunciate a plausible general premise (such as GIU) to avoid harm at the cost of some individuals not being born.

Argument 1B (to support genetic intervention where harms might result because of the lack of consent to the risks involved) fails because the harm avoided by preventing a genetically affected life is part of a package which is, in narrative terms, unable to be regarded as an unalloyed harm and might well be valued by the individual concerned.

Argument 2 (that we should produce the best human lives we can) fails for reasons relevant also to argument 1—there is no plausible general premise supporting it and it relies on an impossibly abstract conception of good.

Argument 3 (that living a damaged life is better than living no life at all) and argument 4 (that each human life is unique and should be respected) both fail because they apply equally to the individual who would be born and to the one already born or conceived but they leave an aftertaste in favour of existing or actual individuals and their relatedness as a basis of positive choices for life.

Therefore, despite its apparent force, the unwitting sacrifice problem and a number of related problems to do with possible lives, wrongful lives, avoiding genetic harm, and so on are problems that cannot be resolved by attending preferentially to premises that look objective and rational but (in their full generality) cut more than one way. The reluctance to be persuaded into ethical activism by the

unwitting sacrifice problem and these premises is supported by the intuition that each human being is an individual who tells an individual story and is therefore more like a work of art than a quantum of impersonal satisfactions.

If that is so, then we are asking, in the ethics of predictive genetic testing, questions of the following type: "Is it better that a Van Gogh painting come into existence than a Picasso". Or, even closer, we might ask: "Is it better that Van Gogh be born than that Picasso be born?" These could only look like morally tractable questions to a person who believed that every human possibility occasions a morally loaded decision.

In fact life faces us with many uncertainties and many of them can be transformed by the way that one addresses oneself to them. Thus there moves into centre stage the narrative voice or voices which express and attend to nuanced attitudes to life as it is lived by an identifiable and partial individual and those with whom that individual has to do. Bernard Williams recommended this moral framework many years ago and it is fundamental to any substantial conception of narrative ethics. Applied to the clinic it suggests that the meaningful stories that structure life and make it worthwhile and the network of supports and relationships around the person living that life make the difference between a life that is liveable and to some extent fulfilling

and a life that is beset by suffering and may end early in suicide. This would seem to return responsibility for the good response to a challenge such as congenital disease to the place it ought to be, while not excluding the choice that some make to not begin a life story that is bound to be attended by certain kinds of suffering.

## REFERENCES

- 1 Redfield Jamison K. *Touched by fire*. New York: Free Press, 1993.
- 2 Andreason NC. Creativity and mental illness: prevalence rates in writers and their first degree relatives. *Am J Psychiatry* 1987;**144**:1288–92.
- 3 Gillett G. *Bioethics in the clinic*. Baltimore: Johns Hopkins University Press, 2004:235–49.
- 4 Glover J. *Causing death and saving lives*. London: Penguin, 1977:62.
- 5 Singer P. *Practical ethics*. Cambridge: University Press, 1979:12.
- 6 Parfit D. *Reasons and persons*. Oxford: Oxford University Press, 1984.
- 7 Rawls J. *A theory of justice*. New York: Oxford University Press, 1971.
- 8 Gillett G. Young human beings: metaphysics and ethics. In: Oderburg DS, Laing JA, eds. *Human lives*. London: Macmillan, 1996:109–27.
- 9 Copeland P, Gillett G. The bioethical structure of a human being. *J Appl Philos* 2003;**20**:123–32.
- 10 Danzer G, Rose M, Walter M, et al. On the theory of individual health. *J Med Ethics* 2002;**28**:17–19.
- 11 Barclay L. Genetic engineering and autonomous agency. *J Appl Philos* 2003;**20**:223–36.
- 12 Moore A, Hope T, Fulford KWM. Mild mania and wellbeing. *Philosophy Psychiatry and Psychology* 1994;**1**:165–78.
- 13 Nietzsche F. *The gay science* [trans Kaufman W]. New York: Random House, 1974:120.

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